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 **NATIONAL HELP LINE**
0300 111 5090

PMRGCAUK is a registered charity established to meet the needs of people with these debilitating conditions by raising awareness, promoting research and offering support.

Changes at the Charity

Penny Denby, became a Trustee of PMRGCAuk at the 2015 AGM in June.

She was elected Chairman of the Charity by the Trustees and takes over from Kate Gilbert, acting Chairman and one of the instigators resulting in the foundation of PMRGCAUK.

Penny says, "I am delighted to have been given the opportunity to help PMRGCAuk develop its support locally and nationally for all who are living with polymyalgia rheumatica or giant cell arteritis."

The number of support groups round the country is increasing. We are extremely thankful to have so many enthusiastic volunteers who run the groups - often single handed. The perfect solution is to have a group in every town. We know that for many of you sharing with others who understand is hugely beneficial.

"To start more groups we need more volunteers and more helpers. If you would like to organise a group or help at a local meeting or if you know family and friends considering voluntary work please let us know.

The online forum helps a growing number of people on a daily basis. If you are not near to a group I recommend you sign up if you have access to the internet. Moderators are all PMRGCAuk members.

"From the beginning of PMRGCAuk Trustees have been actively campaigning for fast track diagnosis for GCA and I sincerely hope it will not be long before the campaign is successful so no matter where you live in the UK you will be offered this. Early diagnosis does save sight."

"The causes of PMR and GCA are still unknown and I am keen that we continue to encourage research in all possible ways.

WELL DONE LUKE!

A huge thank you to Luke Trotter, who successfully completed his run for PMRGCAuk at the Paris Marathon.



Luke's fundraising has surpassed the £500 target and we're incredible grateful to him! Luke is in his twenties, and doesn't have PMR. Find out why he did it on page 6



AGM and Members' Day 2015

On 17 June, members and friends of PMRGCAuk joined the Trustees for the fifth AGM & Members' Day held at the NVCO in London.

The usual AGM business was conducted smoothly, with the retiring Chair of Trustees, Kate Gilbert, speaking briefly about the annual report and the accounts. Readers who would like to read the full report may download it from the Resources section of our website.

The Trustees thanked Robin Hamilton, who had resigned from the role of Treasurer in April due to personal circumstances, for his work on behalf of the charity over the previous two years, and wished him all the best for the future. We also thanked other 'retiring' trustees who have completed at least three years' service on the board – Dr Colin Pease, Lynne Boyle, and Janet Luke.

Two new Trustees, Penny Denby and Dr Sarah Mackie, were elected to the Board. Many readers will recognise their names because of Penny's involvement with support groups, particularly the North Kent group, and Sarah's long involvement in PMR and GCA research.

Sophy Proctor was thanked for the work she had done since she joined the charity - including Newswire and setting up the London support group. Even though she had already started her new job Sophy found time to organise the AGM & Members Day and she has coordinated this edition of Newswire!

All of us present were fortunate to hear two excellent speakers, Dr Toby



Dr. Toby Halliwell

Helliwell and Dr Eoin O'Sullivan. Toby is a GP practising in Staffordshire, with a special interest in rheumatology, who also works as a researcher with the Keele University primary care research group, led by Professor Christian Mallen. Toby spoke about the dilemmas GPs face when dealing with cases of suspected PMR or GCA. Eoin is a researching medical ophthalmologist based at King's College Hospital in



Dr. Eoin O'Sullivan

London, who is leading one of the research projects into GCA jointly funded by PMRGCAuk and Fight for Sight. He gave an enlightening talk on what is going on in the eye during the acute phase of Giant Cell Arteritis, when ischaemic optic neuropathy, which can lead to loss of sight, is a risk. Their presentations raised lots of questions which members explored in discussion groups into the afternoon.

BREAKING NEWS ...

Our patron, Bhaskar Dasgupta, has visited many of the PMRGCAuk support groups round the country but for those who haven't yet been fortunate enough to hear him the exciting news is that he will shortly be recording a series of talks for PMRGCAuk with the latest information to help everyone with PMR and GCA.

The talks will then be uploaded as videos to the internet to be viewed on your home computer. And for those of you who don't have internet access we hope your local support group will be able to show the videos at your regular meetings. If all goes according to plan to have the videos online before Christmas!



£500 RAISED BY NINEVOICES!

£500 was raised this summer by Ninevoices writing group based in Kent. The Kent based group of nine organised their 2015 writing competition for writers worldwide to raise funds for PMRGCAuk and our member, Jane Dobson, who is also one of the Ninevoices, donated funds raised from the sale of her book of poems, 'Fragments of Love'.

Winners of the competition were:

First prize: £100

Sara Kellow from Kent for 'Laptops and Coffin Lids'

Second prize: £50

J. Cammish McKeen, from Buckinghamshire, for 'Stick'

Third prize: £25

Carl Lincoln McCarter-Nyberg, of New York, USA, for 'Reciprocation'

You can read Sara Kellow's winning story at <https://ninevoices.wordpress.com/winner-2015-short-story-competition/>

As a result of such generous donations as this and the monies raised by the Poly Put the Kettle On (see page 7) events PMRGCAuk is able to provide even more help to those with PMR or GCA.

PMRGCAuk support includes our website and social media, free phone helpline, online forum and local groups - all are manned and supported by a great team of volunteers. With more funds like those from Ninevoices and Poly events the charity can train more volunteers to provide even more opportunities.

If you are planning a fundraising event for PMRGCAuk be sure to let us know so we can post information on our website, Facebook and help you in any way we can.

PMR – A GP'S PERSPECTIVE

How important is it to have a GP who not only is sympathetic but really understands your condition?

At our Members' Day in June we were delighted to welcome Dr Toby Helliwell, a GP who also is an active researcher in the Keele University Primary Care group.

Toby is involved in studies into how PMR is diagnosed and managed by GPs. This is very important from our point of view, because we know that about 80% of PMR cases are exclusively diagnosed and managed by GPs, and never see a specialist at all. Toby gave us some insights into why polymyalgia rheumatica presents a challenge to the average GP, both in diagnosis and treatment.

To begin with, PMR is a rather non-specific condition. Faced with a 60 year old woman who comes to the surgery complaining of aching shoulders and fatigue, and not being able to get going in the morning, there is any number of things that could be wrong. Blood tests might give some clues but even they aren't definitive. There are plenty of other conditions that are more common than PMR, so each one of those has to be eliminated from suspicion before the GP will want to prescribe steroids. Toby gave us a list. It included: rheumatoid arthritis, osteoarthritis, shoulder Synovitis, rotator cuff tendonitis, subdeltoid bursitis, capsulitis, depression, giant cell arteritis, hypothyroidism, polymyositis, and neuralgic amyotrophy. If that isn't enough, we can add fibromyalgia, acute or chronic infection, endocarditis, malignancy (multiple myeloma), Parkinson disease, and cervical spondylosis.

Hardly surprising then if the GP

doesn't home in on PMR straight away!

According to Toby, even specialists find the diagnosis challenging, because of the range of overlapping symptoms, and Toby reminded us that during the international classification study (which involved the world's top experts on PMR) 128 PMR patients were identified by the experts. Then it turned out that 12 of these didn't even have PMR, and of those who did, a third of them were hard to be absolutely sure about. Given that these experts identified no less than 68 potential criteria for PMR, it's no wonder that the poor GP is confused and unsure.

Keele University has an ongoing research study to try to understand how GPs go about diagnosing PMR. Initial indications are that one of the most universally used criteria is bilateral shoulder pain (pain in both shoulders). This is bang on with the international classification criteria. Also almost universally used is the raised CRP and ESR markers in the blood tests. However, many specialists agree that in some cases, a patient may have PMR and have normal blood markers. Thirdly, GPs seem to rely heavily on putting the patient on to steroids and seeing how they respond. This may be a favourite strategy. However, it is not one favoured by the experts, who point out that many of the 'differential' diagnoses listed above will also improve on a dose of 20mg a day of steroids. So there is a lot of progress still to be made in educating and raising the awareness of GPs and encouraging them to keep up to date with the most recent guidelines.



GCA and the NHS – Update from the House of Lords

Giant Cell Arteritis has once again featured in Hansard, the record of the Houses of Parliament, thanks to the tireless efforts of our supporter Lord Wills of Swindon, who does a great deal to make sure that the grandees of Whitehall are not allowed to forget the lamentable cases of preventable blindness caused by late diagnosis. Earlier this year, on March 16th, Lord Wills took the opportunity presented by a discussion of the NHS in the Lords to raise the awareness of the noble peers:

“I am grateful to the noble Earl for that Answer, but does he recognise that there is a significant gap between those fine words and what is actually happening on the ground? To take the case of giant cell arteritis, for example, 2,000 to 3,000 people go blind needlessly as a result of it. I hope the House will indulge me for a few seconds if I set out this important example. The condition is easily treatable. Professor Dasgupta, in Southend, has pioneered a fast-track

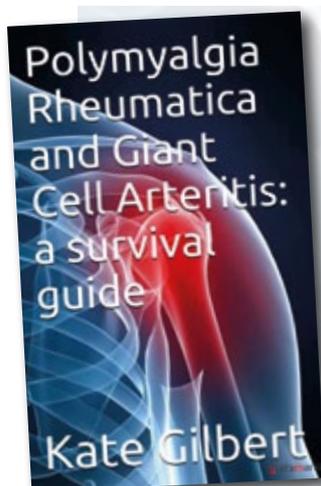
pathway for diagnosis and treatment which has reduced the numbers of people going blind by two-thirds. Rolled out nationally, that would save thousands of people every year from going blind. It would save them and their families needless misery and suffering and would save the taxpayer hundreds of millions of pounds every year.

In January, Sir Bruce Keogh, the medical director of NHS England, wrote to me and said that this “represents a new way of doing things which is better and costs no more. We must learn from such innovative examples”.

Lord Wills followed this up with a question for ‘short debate’ on 11 June, when Lord Prior, a new minister for NHS England, was making his maiden speech. This time, Lord Wills asked what steps Her Majesty’s Government are taking to encourage innovation in NHS England, and once again used the example of the GCA fast-track referral system.

He spoke eloquently and passionately about the economic and human waste of needless sight loss. Some estimates put the total financial cost at about £1 billion over the five years of a parliament. Lord Wills asked why the fast-track, which has been endorsed, is not being rolled out quickly and effectively on a national level.

On one level we know why this is the case. The current structure of the NHS has now placed responsibility in the hands of localised Commissioning Groups and NHS England technically has no power to ‘enforce’ particular clinical pathways, but only to encourage the following of guidelines. Still, Lord Wills clearly believes that more could be done and we are immensely grateful to him for supporting our cause for the last four years. We are also optimistic that things are shifting in the right direction.



Since its publication this book has quickly become a bestseller. Kate Gilbert, PhD. distilled what she learned from having PMR (and recovering!), and from years of working alongside other sufferers, rheumatologists and researchers, as a trustee of PMRGCAuk. Kate says “I have tried to write the book that I would have liked to read when I had PMR, not only when I was first diagnosed, but also a few months in, when I realised that it wasn’t going to be as straightforward as they had led me to believe.”

It is now available in paperback from Amazon.co.uk (Amazon.com outside the UK). Price £5.99 plus p&p. Kindle edition £4.30. Royalties from sales are donated to PMRGCAuk.

If you are unable to order the book from Amazon, write to kate@pmrgcauk.com to order via PMRGCAuk. Or ask your bookshop to order a copy: ISBN-10: 1500713406 ISBN-13: 978-1500713409 Publisher: CreateSpace Independent Publishing Platform (28 Feb 2014)

AN APPRECIATION

I like to think that we all take time to consider now and then the wonderful work done by our chair, Bea, the trustees and the team of volunteers who all work together to make PMR- GCA Scotland such an effective organisation.

It has been so encouraging to see from the Annual Report how much progress the charity has made this past year.

Bea has built up a very willing and hard-working team consisting of the Trustees, Helen, who runs the Helpline and others who man the helpline and run the groups. All these volunteers give of their time and talents very willingly. I just want to remind you that this is not a case of a couple of hours a week. They give many hours of their free time to promote the work of the charity: updating the website, attending national

and international conferences and meetings which often involves travel and overnight stays, dealing with the paperwork, record keeping, answering an enormous number of emails, keeping the financial records and fundraising, mailing the Newswire and other information to the members, manning the Helpline, running groups, representing patients on various medical and musculoskeletal research projects and taking part as volunteer patients for medical student training. All these things take time and patience and several members of the team willingly take on more than one responsibility which is very demanding and time consuming.

If YOU feel that you can contribute in any way to the work of this charity, whether by fundraising, forming a support group in your area or helping with any of the other tasks mentioned,

please make contact by helpline (0300 777 509) or email (info.scotland@pmrandgca.org.uk).

One of the aims of the charity is to promote research. Up till now that aim has been fulfilled by the members completing surveys for research purposes. This year has been an exciting one as, thanks to the Treasurer's fundraising, the charity is now able, for the first time, to donate £1,500 to a research project in Aberdeen (see below).

We do appreciate the work the volunteers do for our charity which has helped so many and continues to do so. I'm sure all of you will agree with me when I say I am so very grateful that Bea, our chair, and her team are working so hard to increase the influence and effectiveness of PMR-GCA Scotland and we wish them well.
Jean Miller (Patron)



At our recent AGM, the trustees proposed making a donation of £1000 to a relevant Scottish based research project.

The membership attending the meeting agreed to donate £1500 to a project being coordinated at Aberdeen University. (The money was saved from a proposed budget reserve of rewriting the website last year, which was ultimately undertaken by a volunteer)

Dr Neil Basu from the university said "...my multi-disciplinary research programme aims to tackle challenges

facing patients with all forms of vasculitis including GCA.

"I manage a vasculitis research fund which pools together generous donations from various sources and which allows us to conduct substantial projects in this specific field.

He also told us "In the future, we do aim to conduct more studies specifically in GCA and, as an example, I have attached a recent abstract (available on request) which we will be presenting next month at the International Vasculitis Conference in London. This is a small retrospective study detailing the promise of Mycophenolate for some GCA patients. One possible outcome of this work will be to integrate data from other large centres to examine whether our positive experience is consistently observed. I have already

had conversations with Prof Justin Mason from the Hammersmith about this possibility."

Lorna Neill and Christine Ritchie attended the University to meet with Dr Basu and present the cheque on Friday 15th May 2015.



HELPLINE

0300 777 5090

www.pmrandgca.org.uk

Registered Scottish Charity No
SC037780

Registered address
Forest Lodge, Foulden,
Berwickshire TD15 1UH



Kate takes shelter



Well done Luke

(cont from p1)

So why did a young man with no experience of PMR or GCA do so much to raise awareness?

Luke told us: "My mum, Jilly, was diagnosed with PMR in July 2012 after over 2 years of being misdiagnosed by doctors. She had been sent to a range of consultants across Sussex who didn't recognise her symptoms because of the lack of information available to them. My family were worried she might have a serious degenerative condition as she could barely walk upstairs and had extreme difficulty in getting out of bed. PMR was overlooked at this stage as she was considered to be "too young" at 55 to be suffering from this.

I ran the Paris Marathon on Sunday 12 April to raise awareness of PMR and GCA, to help PMRGCAuk fund practical and emotional support to sufferers, and to support further research into preventing these debilitating conditions".

Kate takes the high road

"I'll do it with you Di!" Little did I realise what I was letting myself in for.

We had been talking about plans for the year ahead, and my dear walking friend Diane had said that she wanted to do the Dales High Way to celebrate her 70th birthday, but she had nobody to do it with. How hard could walking 90 miles in the Yorkshire Dales National Park be? I volunteered to be her walking companion, and, five months later, at the end of April, we set off from Saltaire on a drizzly Saturday morning, to arrive in Appleby in Westmoreland, six days and a hundred miles later, having survived everything that the bleak moorland landscape could throw at us.

Now recovered from PMR, I wanted to take on a physical challenge to test my strength and fitness. I wanted to show myself that it is possible to get back one's vigour and 'oomph' after enduring PMR. Di and I had done a fair bit of training, with a couple of long hikes around the woods and trails of South Staffordshire, a brisk yomp up and down the Wrekin, then up and down the Wrekin again, and an intrepid walk from Birmingham to Wolverhampton along the canal towpath, taking in a fascinating landscape of scrubby hedgerows and corrugated iron. But nothing could really prepare us for the challenge of walking 20 miles a day, ascending from the bottom of the dales to the tops of the moors, the wind in our faces and the rocks at our feet, hour after hour just putting one foot in front of the other, and dreaming of a cup of tea. It was amazing. A landscape that I had never seen before, breathtaking in its beauty and grandeur, unfolding beneath our feet.

The first day took us to Skipton, via Ilkley Moor, and the second to Settle, passing over Malham Cove. Day 3 saw us conquer the peak of Ingleborough, with its stunning view right across Morecombe Bay, and the steep descent to Chapel-le-Dale. We flopped into our B and B, drew

the curtains and had our showers. Then I opened the curtains again and couldn't believe my eyes. A carpet of snow! The next morning dawned brisk but dry, and we set off again, admiring the stunning view of the Ribblesdale Viaduct, and feeling pretty pleased with ourselves. Four hours later and we were sheltering like sheep from a blizzard, crouching behind a dry stone wall. When we finally got down to the village of Dent we found that all the food in the pub had been eaten by a rambling group who had got there before us. Thank goodness our host John had given us some sandwiches for survival rations!

Unfortunately the weather didn't improve a great deal. The previous week had been lovely. If we had done the walk then we would have been complaining of sunburn. As it was, on Day Six we had to turn back off Horton Fell because of a blizzard that made the track completely disappear. We didn't want to be a statistic in the mountain rescue records. But every cloud has its silver lining. Because we went the long way round we discovered the Cross Keys, the temperance inn near Sedburgh, and met the lovely Quaker community who keep it going to provide tea and sympathy for tired travellers like us.

By the time we reached Appleby-in-Westmoreland, along an enchanting riverside path, we felt that we had not only covered many miles, but also travelled back in time to a simpler, slower, and quieter way of life. That feeling stayed with me for quite a while after we finished – it had been almost like a retreat. And how wonderful it was to come back home and discover that the walk had raised £1400 for PMRGCAuk! Thanks so much to all of you who generously sponsored me and sent messages of encouragement – you certainly put a spring in my step!

Kate Gilbert

Poly put the kettle on!

Sally Ann Morgan reports from Plymouth:

We held our Poly put the kettle day on the 16th April at Camelhead Sheltered Housing Community Centre. The afternoon was a great success. We had over 50 people in all calling in and most stayed for the afternoon.

Our members both male and female all bought their homemade cakes and they were all fantastic. I know because I just had to try them all to make sure they were okay. We had a craft stall by Hazel Stock with donations from her crafting club, Wendy Wilson had her hand massage table and our entertainment was our very own fundraiser "Just Derek". We had lots of items donated so over 30 raffle prizes and the whole 2 hours raised £200.00. Our group did us proud.

After a few anxious days and nights, we had a fantastic day with lots of fun and laughter and lots of awareness for PMR/PMRGCA.

In the next edition of Newswire we will have a report on the Poly Put the Kettle On! event in Taunton. If you are planning a Poly Put the Kettle On! event in your area please tell us all about it.

RESEARCH UPDATE

How do GPs manage suspected GCA?

These days we are getting used to hearing the expression 'It's a postcode lottery'. So it shouldn't come as any surprise to learn that there is quite a lot of variation around the country in how GPs deal with suspected cases of Giant Cell Arteritis when they walk into the surgery.

A survey of 5000 GPs chosen randomly, indicates that GPs have quite a range of approaches. The survey, carried out by the Primary Care research team at Keele University, was answered by 1249 GPs (25%), a good response by research standards. It asked questions about family doctors' experience of diagnosing and managing GCA, and there was a mixture of closed questions, to gather statistical information, and open text questions, which helped to gather more thematic information about what GPs think. It emerged that many GPs are concerned about the lack of fast track pathways to support patients with suspected GCA. Often a GP will feel frustrated, trying to access specialist care for their patient, although guidance suggests that specialist review should be prompt. Some GPs even have to arrange a temporal artery biopsy themselves before a specialist reviews the case.

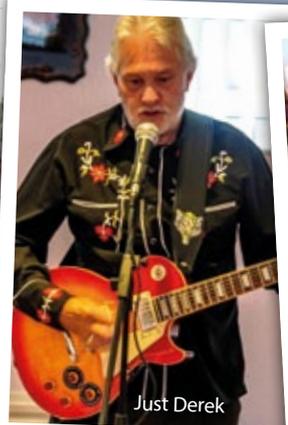
Just 20% of responders said that they would refer a patient immediately to hospital without doing other investigations such as blood tests, and one in eight (16%) said that they would only refer if the initial investigations came back with abnormal results. About half of the GPs who responded said that they would start treatment with steroids before referring the patient. About 40% of doctors would refer to rheumatology services, and about one in three to ophthalmology services. One in ten would refer to general medicine, and only 3% would send the patient to A and E.

The study concludes that there are 'marked differences' in the treatment and assessment of patients with GCA in the UK, and that this reflects the conflicting referral pathways and difficulties GPs have in accessing 'appropriate services'. Many GPs would not initiate immediate treatment, contrary to current guidance. So not surprisingly, focused clinical education of GPs is advised, to improve outcomes for people with Giant Cell Arteritis.

Ref: How do General Practitioners Manage Suspected Giant Cell Arteritis? Dr T Helliwell, Dr Sara Muller, Dr Samantha L Hider, Dr Jane Richardson, Prof. Christian Mallen. Research Institute for Primary Care and Health Sciences, Keele University, Keele, Staffs, ST5 5BG, UK.



Setting up outside



Just Derek



Cakes!



The Sunflower Choir



HealthUnlocked

Join our PMRGCAuk community and make your experience count



Get help to manage your health and lifestyle from others with polymyalgia rheumatica and giant cell arteritis and from the charity, PMRGCAuk.

It's free, easy to use and it's just waiting for you!

The online community gives you:

- Answers to your health questions from other patients
- Support from other PMR and GCA sufferers
- Ideas for treatment and lifestyle choices that could help
- Health issues and debates relevant to you

Take control of your health and join today

pmrgcauk.healthunlocked.com



Support group contacts

The very latest information for all support groups can be found at www.pmr-gcauk.com including details of speakers and local events. If there isn't a group near to you why not consider starting one – a problem shared is a problem halved! We will help you to get started.

CAMBRIDGE

Organiser: Dale Hodgson
Phone: 0300 999 5090
Email: cambridge@pmrgcauk.com

EAST ANGLIA

Organiser: Maryan Fidler.
Phone: 0300 999 5090
Email: eastanglia-pmr-gca@outlook.com

GREATER LONDON

New group just started!
Phone: 0300 999 5090 for more information
E-mail: info@pmrgcauk.com

LINCOLN

Organiser: Rob Murton
Phone: 0300 999 5090

NORTH EAST ASSOCIATE CHARITY

Organisers: Pam Hildreth & Mavis Smith
Phone: 01287 623 334
E-mail: pmrgcafightersne@googlemail.com
Website: www.pmr-gca-northeast.org.uk

BROMLEY & NORTH KENT

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MANCHESTER & NORTHWEST

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Email: northwest@pmrgcauk.com
Website: www.pmr-gcauk-nw.com

PETERBOROUGH

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SURREY

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